



The Honorable Gregg Harper  
U.S. House of Representatives  
307 Cannon House Office Building  
Washington, D.C. 20515

Dear Congressman Harper,

Global Genes | RARE Project is one of the leading rare and genetic disease patient advocacy organizations in the world. What began as a grassroots movement in 2009 with a few rare disease parent advocates and foundations has grown to over 800 global organizations. Our mission is centered on increasing rare disease awareness, public and physician education, building community through social media and supporting research initiatives to find treatments and cures for rare and genetic diseases.

We, along with the organizations listed below, are writing to support **The Kids First Research Act of 2013 (H.R. 2019)**. This bipartisan bill would eliminate taxpayer financing of presidential campaigns and party conventions and reprogram those savings to provide for a 10-year pediatric research initiative through the Common Fund administered by the National Institutes of Health.

During these trying fiscal times, we are pleased to see efforts that would increase funds for pediatric research.

Unfortunately, pediatric research is terribly underfunded and largely overlooked, as medicines and devices are often untested in children. Children are usually prescribed medications that have only been tested in adults, which is unacceptable. Children are not adults. More efforts must be made to properly research drugs and devices in the pediatric population, and this is an important step in that process.

We are pleased to express our strong support for H.R. 2019, and believe this legislation will help to bring increased funding and awareness to pediatric medical research. We look forward to working with you and your staff to ensure this bill is enacted into law.

Sincerely,

Global Genes | RARE Project  
Alstrom Angels  
Cure AHC  
Dravet Syndrome Foundation  
FMDSA  
Gavin R Stevens Foundation  
GT23 Foundation  
Gwendolyn Strong Foundation  
Hannah's Hope Fund for GAN

Global Genes | RARE Project  
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Hereditary Disease Circle  
I Have IIH Foundation  
Jonah's Just Begun  
Joshua Hellmann Foundation for Orphan Disease  
Klippel-Feil Syndrome Alliance  
Little Miss Hannah Foundation  
MPS Society  
National Gaucher Foundation, Inc.  
National Tay-Sachs & Allied Diseases Association, Inc  
Noah's Hope  
Noonan Syndrome Foundation  
Rasopathies Foundation  
Sanfilippo Foundation for Children  
Sarcoma Foundation of America  
Stop ALD Foundation  
Team Sanfilippo  
U.R. Our Hope

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